



THE DIFFICULT, DEMANDING, AND DEMENTED AIDS PATIENT IN LONG-TERM CARE

NANCY NEVELOFF DUBLER, LLB

ABSTRACT Demented AIDS patients in long-term care present interconnected medical, ethical, and management problems. The patient's right to care must be considered in the context of the obligations owed to other residents and to staff members. A principled analysis should focus on substantive and procedural issues: the concept of autonomy must be modified by notions of accommodation to the needs of others; procedural fairness should guide discussions. A dynamic analysis should identify the various parties, their conflicting interests, and possible routes for resolving differences.

KEY WORDS Ethics, Long-term Care, Autonomy, Accommodation.

Narrative

The setting is a large Victorian house in a residential area not far from one of the large universities in Sydney, Australia. There is a brand new, 6-foot-high wooden fence around the property, still smelling fresh as sawdust; one must ring the bell to be buzzed in or out. On the first floor is a set of sitting rooms. People are watching television, reading, or playing pool in a corner. Upstairs are a number of rooms that are not visible from the turn at the top of the stairs and a large sitting room in the front with a bay window; it is bursting with bodies. These persons, sitting on the couch, the windowsill, even pillows on the floor, turn out to be the staff of the house, which is a long-term care facility for persons with AIDS. Despite the newest treatments, these patients are symptomatic and in need of residential services and medical supervision. Many of them have some degree of dementia.

Twenty-eight staff members have gathered in the second floor sitting room, including counselors, drug treatment specialists, physicians, social workers, rehabilitation and occupational health specialists, the chief physician for the facility, and the representative from the Ministry of Health for the state of New South Wales, which funds the residence. Two of us were specially invited guests for the discussion, a doctor of philosophy/bioethicist who is connected to one of the hospitals in Sydney and me.

The patient presented was a 37-year-old patient, renamed John for the discussion, who

Ms. Dubler is Director, Division of Bioethics, Department of Epidemiology and Social Medicine, Montefiore Medical Center, 3347 Steuben Avenue, Bronx, New York 10467, and Professor, Bioethics, Albert Einstein College of Medicine.

had been symptomatic with AIDS for 14 years. This was his first year at the residence. He had lived alone for some of the time of his illness and had also lived with his parents. His family had decided that he needed more supervision than they could provide and had helped him to apply to the residence.

He had presented problems from the outset. He was quite demented and very demanding. He wanted attention all of the time and seemed not to remember that he recently had been part of a discussion or group watching television. He wanted one of the staff to be with him almost constantly. Although a long-term drug and alcohol user, he seemed to have stopped using drugs. However, he did continue to crave alcohol and used every opportunity to try to reach a drink. Before the new fence was built, as an attempt to control the behavior, he would leave whenever possible and go to any one of a number of pubs and order alcohol. As he never had the money to pay, he needed to rove further and further from the residence to find an innkeeper who was not savvy to his pattern. He would then hail a cab to return him to the residence and, when he had arrived, announce to the driver that he could not pay. He presented a generally disinhibited approach to the rights of persons in the world outside the residence.

The patient's health status was stable. He was taking antiretroviral medications under a directly observed therapy (DOT) program supervised by the staff. He had no detectable viral load and a T-cell count of over 500, indicating that his health status, in regard to his AIDS, was quite good. Whereas his general health status had improved with multiple therapy, there had been no improvement in his dementia; he was only adherent with the medical regimen with the supportive process that the residence provided.

In the month before this meeting, the patient had set fire to his room while smoking in bed. Smoking in bed is not permitted under the rules of the residence, but the patient regularly ignored rules that conflicted with his desires. The other inhabitants of the residence, especially his roommate, were extremely worried about future fires. As a result, he had been given a single room; a bed check every night attempted to determine whether matches or cigarettes had been secreted within reach.

There was no locked room in the facility, but there was a "drying out" room where the patient was placed when he managed to leave the facility and returned drunk and disorderly. The fence had been an attempt to control this behavior and had been partially successful.

This narrative of the patient's recent history, attitudes, patterns of behavior, and problems was presented as the opening of this multidisciplinary conference. The staff were very concerned about the rights of this patient in the context of the rights of others, both residents and staff. They were concerned that the attention provided to this patient was excessive, but were unsure how to go about setting limits. As a confounding factor in considering the rights and interests of this resident, he had a legally appointed guardian who had very clear ideas of how she wanted her ward treated in the context of the residence. She wanted no chemical or physical restraints used and wanted him to "have the attention that he needs" to be comfortable.

ISSUES FOR THE STAFF

The staff articulated the following questions and concerns:

- how to manage the generally demanding behavior, the drinking, and the dangerous patterns, such as smoking in bed;

- how to balance the patient's wishes for freedom of movement and choice against the real dangers for the other residents;
- how to balance the very real needs of this quite demented patient against the needs of the other residents within the need to define an appropriate workload for the staff;
- whether it was appropriate to exercise the state's power to protect others from this patient and to claim that he was a "danger to himself and others" as a way of placing him in a locked facility in a psychiatric institution;
- whether the guardian had the right to dictate the terms and conditions of the patient's stay at the residence;
- whether some degree of pharmacologic sedation would be appropriate despite the guardian's objection to control of some of the most disruptive of the patient's behaviors and whether that would be better or worse than some sort of physical restraint;
- assuming that the patient did not like this sedation—he had complained previously that some of the medications made him drowsy—whether the staff could ignore his refusal and continue to medicate him nonetheless;
- how to conceive of the rights of a severely demented patient who is unaware of his dementia, but whose behavior, because of this dementia, is detrimental to the staff and residents of the facility and bothersome to others in the larger community in which the residence is located;
- how to characterize and credit the annoyance to the pubkeepers and the cabdrivers in the community, who regularly had their provisions and services stolen by the patient;
- how to draw the line between social control and medical care;
- whether to consider stopping antiretroviral therapy as one alternative possible response to this patient's uncomprehending behavior.

There are a few more facts about this case that are important in the history of this patient and the setting in which the discussions takes place. There is no other residence for this sort of patient in the city or in the surrounding locality. His family had made clear that they would not take him in. The secure psychiatric wards had experience with the patient and would not accept him for any extended length of time. He could not manage on his own, and if this residence rejects him, he is on the street.

A PRINCIPLED ANALYSIS

A series of premises undergirds the discussion that follows. The first premise is that the rights of patients are most in danger from secret and hidden actions by

persons in power who act alone or in private without open consultation with and critique by others. In this case, the very existence of a multidisciplinary meeting with all of the stakeholders present ensures some degree of protection for the resident. It requires collaboration on options and, it is hoped, anticipates a consensus as the basis for an action plan. The second and related premise is that, in matters of uncertainty when an appeal to principles fails to identify the clear action to be followed or in complex circumstances when the solution results from the delicate balancing of the rights, duties, and obligations of many parties, a clear process for deciding is part of the solution. Another way to think of this second premise is that, when substantive justice is unclear, procedural justice may shoulder some of the burden of fairness.

Both of these premises lead to one intermediate suggestion: In complex cases, an open and fair process that brings all of the stakeholders into one room and permits them to articulate their worries, fears, and professional evaluations is central to devising an ethical solution. An open process protects the patient's rights by permitting the identification of opposing positions, by exposing choices (both real and perceived to a broader analysis), and by helping all to participate in and experience the process of balancing the rights of the patient against the rights of others—the essence of this case. In this case, the rights of the patient to request, choose, or demand care can be examined in the context of competing rights and interests.

There is one last premise; this one is more complex and perhaps somewhat controversial. In complex situations in which housing and medical care are at issue for a patient/resident, the applicable ethical principle to be applied is not only autonomy, but also the principle of accommodation. This notion of accommodation was developed in the context of thinking about home care in contrast to acute care, and this sort of residential community is most like a home.

It is accepted generally that, in the realm of patient choice of interventions in both the acute and the ambulatory care settings, the values, preferences, and idiosyncratic choices of the patient govern the care provided. The autonomy of the patient is limited, however, when patient choice may put others at risk by causing harm. Thus, among the useful instrumental ethical precepts is the harm principle. It would dictate that, if the patient could harm others by not taking medicine for active tuberculosis, for example, thereby remaining able to spread the disease, the patient could have his or her autonomy to refuse care limited and could be ordered to take medication. However, for most patients who are capable decisionally of making medical choices and are supported in the process of providing voluntary informed consent, the process of choosing need not take

into account the needs of others. Admittedly, most patients who live in families in which they are loved and in which they offer love often take the needs of others into account when they reach a decision about care. But, the fact remains that they are not required to do so by the commonly understood ethic of informed consent. Whether a patient agrees to surgery is a decision that emerges from the individual decision calculus that engages the patient. If the patient and the family disagree or if the patient and the medical staff disagree, it is the patient's choice, based on the patient's self-perceived needs, values, and personal narrative, that controls the future.

In home care, and residential long-term care centers are like homes, the autonomy of the patient and the patient's wishes, values, and desires are only one factor among a number of factors that must be taken into account. If, for example, a patient declares that he is going to be discharged from a hospital to the home of his daughter, and his daughter states that she works, has three little children, and cannot manage her father in her home, the wishes of the father do not prevail automatically. Indeed, they likely will fail in light of the daughter's priorities and life stresses. The patient's desire is no more powerful or weighty than the positions, needs, and ability of the daughter. The wishes of the patient need to accommodate the interests and choices of the daughter. Accommodation, not autonomy, is key to understanding the ethical terrain.¹ In acute care, by which the body of the patient is affected directly, the principle of autonomy and the legal correlate—self-determination—determine the balance of decision-making authority. In decisions about setting that involve the interests of others, the autonomy interests of the patient must be balanced against the rights, duties, and interests of others in a process that can be characterized best as one of accommodation.^{2,3,4}

In this case, John's wishes, needs, and desires must be balanced against the needs of the other residents and the dimension of the total demands on the staff. He cannot have the full attention of one or another of the staff at all times. There are not sufficient hours of staff time to provide for this intensity of care unless the needs of some of the other residents are either ignored or shortchanged. In this setting, with a fixed and global budget reaffirmed during the discussion by the representative of the Ministry of Health, the more attention John gets, the less there is for others. The more gates and locks are added to restrain John, the more the freedom of all is diminished.

Some might argue, however, that as this residence is a hybrid, both a home and a medical facility, it has enhanced obligations. It cares for AIDS patients who have chronic disabilities because of their illness and who need a place to

be while they receive care. But, these are not acutely ill persons, and the relationships of the staff to the patients are as counselors primarily and not as clinicians. Physicians are available to the staff and consult on regimens as needed. This is a classic long-term care facility in which medical issues mix with lifestyle and comfort factors. Because this is a mixed-use facility, the staff's need to accommodate the patient is more substantial than would be the case for a family member, friend, or other nonprofessional. Nonetheless, the obligation to care exists in the context of the needs and wants of other residents.

Having considered the relationship between autonomy and accommodation and having identified the need for an open process for balancing rights and interests, there are additional ethical principles that are implicated in this narrative: allocation of scarce resources, respect for persons and the protection of vulnerable patients, and obligation of health care providers to promote health and well-being.

ALLOCATION OF SCARCE RESOURCES

In thinking about the resources, both financial and person power, it is important to make the initial distinction between scarce and expensive resources. In theory, more staff is merely a matter of expense, in contrast to an actually scarce resource such as a solid organ for transplantation. In theory, there could be more money made available to the residence to hire more staff to care for John. But, the representative of the governing agency made clear that there would be no budget supplement to solve this dilemma. By this decision, a merely expensive resource became finite and restricted. Given these budget realities, the staff has been converted from an expensive resource into a scarce resource. The question is, how must that resource be divided to meet the imperative of justice for all of the residents?

Most commentators who have addressed issues of the allocation of scarce resources have identified three ways in which demands of justice can be satisfied: first, by place in line (first come, first served); second, by a lottery; third, to the neediest, who can benefit most before all others (triage). Once the threshold has been crossed, there is a principle of equality: give to all in as equal a portion as can be managed using the finest markers possible for the division.

This residence relies on a combination of entrance factors. It admits those who were first in line, who are the most needy. Once they are at the facility, the staff tries to allocate its attention to all of the residents in an equitable fashion, although until John's case, this was not a well-discussed principle of the staff, merely a working assumption.

In this case, all of the residents admitted to and located at this long-term care facility have needs for care, caring, and attention. It follows that all residents deserve the care to the degree that it meets their needs and does not detract from the care needs of others. The application of these principles would seem to point to the outcome that John must receive less so that others can receive a more justly proportional slice of the pie.

RESPECT FOR PERSONS AND THE PROTECTION OF VULNERABLE PATIENTS

The principle of respect for persons is divided generally into the subprinciples of respecting the autonomous choice of capable patients on the one hand and protecting noncapable patients from harm on the other. Respect for persons requires that one begin by identifying the patient's category, whether the patient is capable or incapable. If capable, the decision process of the patient should be supported and the resulting choice respected. If the patient is vulnerable, cognitively impaired, confused, demented, or delirious, providers must search for the prior values of the patient, determine if an advance directive exists, identify the natural or appointed surrogate who may be the repository of patient expressions and values, and protect the patient from having others make decisions that are not according to his or her values or in his or her best interest.

In this case, I am assuming that all of the residents of the facility are in some way disabled and, therefore, have needs that must be assessed and protected. Certainly, other patients and staff are at risk from a patient who smokes in bed and causes fires. Others are also at risk, although in more subtle ways, from the reputation for dishonesty and stealing that John has begun to spread around the neighborhood. The collective reputation of the facility and its inhabitants is likely to suffer, and all residents may be treated with less respect by neighbors and provisioners.

OBLIGATION OF HEALTH CARE PROVIDERS TO PROMOTE HEALTH AND WELL-BEING

The goal of health care is to promote the health and well-being of the patient. When the patient is disabled and cannot be his or her own advocate, others must make the tradeoffs between quantity of life and quality of life. Sometimes, the choices are clear. If a demented patient must be restrained and sedated three times a week to be moved to dialysis and if he or she screams throughout the process despite the sedation, the issue of whether or not to continue dialysis will need to be addressed. The issues in John's case are more subtle. John is happy and doing well with the disproportionate share of staff time he is receiving. Conflicting obligations to staff and other residents, however, demand that the

present plan not continue. Realistic future care options include new medical regimens, use of chemical restraints, use of physical restraints, and perhaps even discontinuing his basic AIDS regimen, which will likely lead to infection and death. How should this choice be made?

John cannot be helpful in choosing among the options. One might attempt to elicit information about his values from his family. But, there is another player in this case, the guardian. This court-appointed person seems, from the description of staff, to assume that her choices for the patient trump all other considerations. She will need to be disabused of this belief. In the same way that the patient's family, or the parent of a child, cannot demand what would amount to an unethical allocation of scarce resources, so, too, the guardian should be restrained or at least educated to the limits in the exercise of her power. In addition, she can be forced to bear some of the burden of the decision process. Let her choose between ending his life and restricting it in some ways. She will almost certainly choose the latter, as she should. In this case, the existence of the guardian can be seen as a support for a fair resolution. Were she, based on the values of the patient, to choose to discontinue his medications—if his response to the restrictions were so extreme and unhappy—this would be strong, legally sanctioned, support for this choice.

I suspect that no one in the room actually advocated stopping the patient's AIDS treatment. The issue reflected the extreme frustration of the staff with the demanding patient and distant, directive guardian. But, the discussion does foretell discussions that might emerge in the future as longevity comes in conflict with quality of life. All participants at the meeting agreed that no present guidelines exist on this matter, and that any policy on withholding care would need analyses by medical, ethics, and public policy experts before being considered by clinical staff.

A DYNAMIC ETHICAL ANALYSIS

The principled analysis above is one way to approach an ethical deconstruction and resolution of this case. There is another route, however, and that path employs a dynamic approach to the issues, players, and conflicts in this case. A dynamic analysis asks: Who are the parties to this case? What are their interests? Are those interests in conflict? If so, how might one think of resolving those conflicts? In this case, the parties are numerous. They include John; his guardian; his family; the various members of the staff, from those who are very committed to the patient to those who have minimal contact and see him as a burdensome problem; the other residents in the home; the members of the department of health, who

are responsible for the functioning of the residence; and the members of the community, who come into contact or are swindled by the patient.

All of these parties have an interest or a stake in the plan that will be crafted finally to manage John. Some have related and aligned interests, and some have interests that are in opposition. The effort to delineate these will make the tradeoffs clear and permit the deciding team to calculate the benefit and burden of each option to each of the implicated parties. It will also permit the construction of a hierarchy of the parties that will help to order their various interests. The pub owners who get cheated out of payment have a less weighty interest than the other residents of the home, who might be burned to death in a fire started by John.

Identification of the parties, their interests, the weight of those interests, and the order of priority is the first step of a dynamic analysis. It should be engaged in by as many of the responsible and interested parties as can be assembled. This gathering then facilitates the next step, which is the brainstorming of options or solutions. It is my experience that a larger number of smart and concerned people in one room will come up with a larger number of possible ideas than a smaller number. Someone may have experience with one sedative that seems to calm without numbing. Someone else may know of the patient's connection with one or another of the staff or residents that might be useful in redirecting his energies. The object of this step is to maximize options and to try to arrange them in some reasonable order.

The sequence of possible care plans or interventions that the group reaches should be self-executing. That is, if all other attempts at control have failed, escalating sedation will be tried until the patient is manageable. This plan can then be shared and negotiated with the guardian. (Needless to say, it would have been best to have her as a part of the process, but she declined the invitation.)

CONCLUSION

As AIDS is transformed from an acute, life-threatening event to a chronic illness, the ethical dilemmas that it creates will evolve to reflect the new face of the epidemic. At the beginning of the epidemic, the issues presented involved treatment by health professionals; discrimination by health, insurance, and other domains of society; and funding for and access to care. In this next stage, the issues, at least in this and other wealthy and developed countries, will center around access to multiple drug therapies for the less organized—drug and alcohol users and the mentally ill—and management of long-term infected persons over the trajectory of the illness. Increasingly, this will involve the management of

demented persons whose disease is stable, but whose cognitive skills and judgment have declined. These are the sorts of issues that will be central to the medical care of the HIV-positive chronically ill cohort as the population grays and requires greater levels of support for management in the community.

AIDS patients becoming demented will present special problems, however, for as disinhibition increases and judgment declines, the public health imperatives that protect against the spread of the disease become less effective. In the case of John, for example, the analysis of his rights would be very different if it were discovered that he was having unprotected sex. That behavior would invoke the harm principle and demand restrictive action to protect others. In John's case, this was raised explicitly in the discussion. His primary counselor explained that this was not a problem and that what was likely to become ever more of a problem was that his habit of masturbating was becoming less private, more public, and more disturbing to the other residents and staff.

The ethics of long-term care is the ethics of the home with the overlay of professional medical responsibility. It requires a process of balancing the preferences, interests, and rights of the patient against the corresponding rights and interests of other parties. It requires having a public, or at least a transparent, process by which the concerns and insights of the professional and residential communities can be identified and analyzed. The ethical issues in the care of persons with AIDS have not disappeared; they have changed and evolved to meet the new face of the epidemic.

REFERENCES

1. Dubler NN. Accommodating the home care client: a look at rights and interests. In: Zuckerman C, Collopy B, Dubler NN, eds. *Home Health Care Options: a Guide for Older Persons and Concerned Families*. New York, NY: Plenum Press; 1990:141-166.
2. Collopy B, Dubler N, Zuckerman C. The ethics of home care: autonomy and accommodation. *Hastings Cent Rep*. March/April 1990;(special Suppl).
3. Arras JD, Dubler NN. Introduction: ethical and social implications of high-tech home care. In: Arras J, ed. *Bringing the Hospital Home: Ethical and Social Implications of High-Tech Home Care*. Baltimore, MD: The John Hopkins University Press; 1995:1-31.
4. Arras JD, Dubler NN. Bringing the hospital home: ethical and social implications of high-tech care. *Hastings Cent Rep*. September/October 1994;(special suppl).